

MEDIA RELEASE

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FAMILIES WELCOME HISTORIC NSW GOVERNMENT INVESTMENT TO HELP CHILDREN WITH JUVENILE ARTHRITIS

- **NSW Health Minister announces record \$6.9m to fund vitally needed health specialists**
- **Thousands of children to benefit as state government invests in multidisciplinary paediatric health teams**

Thousands of NSW children living with painful and incurable juvenile arthritis are set to benefit from a NSW government budget announcement, investing a record \$6.9m in additional specialist paediatric services.

NSW Health Minister The Hon. Ryan Park has announced significant funding for much-needed multidisciplinary services throughout the state including additional specialist paediatric rheumatology doctors, nurses and allied health workers dedicated to juvenile arthritis and related childhood rheumatic diseases.

Juvenile Arthritis Foundation Australia (JAFA) founder, Associate Professor Ruth Colagiuri said, “This history in the making. This announcement rectifies generations of under-resourcing for this neglected disease - bringing it out of the dark ages and into the 21st century.”

Juvenile arthritis affects approximately 6,000 to 10,000 Australian children aged 0-16 years. Most live with daily pain and, without access to treatment, can progress to lifelong disability and loss of vision. Despite the prevalence being similar to diabetes and epilepsy in children, there is currently only one full-time equivalent paediatric rheumatologist in NSW, long waiting times and low awareness of juvenile arthritis.

Prof Colagiuri said, “This funding will be a game-changer, providing expanded and faster access

to the highly specialised care to help our children avoid lifelong pain and disability. JAFA sincerely thanks the NSW government and Minister Park who have listened to our advocacy, clearly understood the need and committed the largest ever tranche of funding by any state government to improve the care of children with arthritis and related rheumatic diseases.”

Adam Peacock, father of 7-yearold Nylah said “This new funding will make a massive difference to appointment times and getting help to manage Nylah’s pain and acute episodes of her arthritis that are so unpredictable.”

“The extra help this funding will provide will make a big difference to a lot of kids who are struggling, and their parents. We’re lucky because we live in the city but people in rural NSW have it a lot harder than us because they have to travel to Sydney for their child’s care, so it is particularly good news for them,” said Tanya Dmitrinow, mother of 9-year old Leo.

The funding announcement was made on Radio 2GB’s drive program, hosted by journalist Chris O’Keefe, who revealed he suffered from a form of juvenile arthritis from the age of 11.

Chris told his listeners, “Every single joint in my entire body was inflamed – wrists, knees, ankles, you name it. And it really, really hurt. At first it was dismissed as growing pains.....it got progressively worse and it took 12 months for Mum and Dad to get a proper answer from anybody and I was in a wheelchair at times. I was on crutches for most of it and the pain was so excruciating.....I couldn’t live a normal life.”

Prof Colagiuri said, “Chris’s story is more than 20 years old but sadly is still very common. We are immensely grateful he has shared it and following the budget announcement we look forward to a more positive future for children with juvenile arthritis.”

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**Available for interview:
A/Prof Ruth Colagiuri, Mobile: 0408 648 235**

Adam Peacock, Mobile 0407 939 502 - parent
Tanya Dmitronow, parent

Health Minister's media release

https://www.nsw.gov.au/media-releases/largest-ever-nsw-investment-into-care-for-children-juvenile-arthritis?utm_source=miragenews&utm_medium=miragenews&utm_campaign=news

2GB Interview

<https://www.2gb.com/nsw-govt-announces-7-million-funding-for-juvenile-arthritis/>

For more information: www.jafa.org.au

Download video clips of children living with juvenile arthritis:

<https://www.youtube.com/watch?v=5X7xbnAM5f4>

About JAFA

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation for children and young people with arthritis and related childhood rheumatic diseases and their families and carers. JAFA is a registered charity, founded in 2019 by Associate Professor Ruth Colagiuri AM and Professor Stephen Colagiuri AO to:

- Raise awareness among health professionals, politicians and governments, the education sector, the broader community, and potential funders
- Lobby governments to provide optimal and accessible health care and support for children, adolescents and young people with arthritis and their families and carers
- Influence and partner with funders to invest in research for better treatments, prevention and, ultimately, a cure.

Background

Juvenile arthritis (JA) and childhood rheumatic diseases (CRDs) are painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JA/CRDs are estimated to affect some 6,000 to 10,000 Australian children aged 0-16 years making it similarly prevalent to childhood diabetes and epilepsy. 80% of children with JA experience daily pain and suffer a high burden of permanent disability, time off school and lost educational opportunities, social and physical marginalisation, and mental ill health. 20% of children with oligoarticular JA will also have uveitis - an inflammatory eye disease that causes visual impairment, cataracts, glaucoma, and eventual blindness.

In 70% of affected children, arthritis continues into adulthood accounting for tens of thousands adults with disability. The average time from the onset of symptoms to a diagnosis of JA in Australia is 11 months. For some children the delay is much longer thus critically delaying the commencement of treatment which aims to avert damage to joints, eyes, skin and organs by driving the inflammatory process into early remission through the use of powerful immuno-modulating medications, steroids and anti-inflammatories. These drugs can have serious side effects.

All children with JA/CRDs require ongoing regular clinical monitoring and rapid access to specialist multidisciplinary teams (MDTs) is essential. Paediatric rheumatology services in Australia compare poorly with those in equivalent economies internationally, and with services for similarly serious and prevalent chronic childhood conditions within Australia. Consequently, JA/CRDs represent a major area of inequality and risk in the Australian health system.